TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Morwell — 5 December 2016

Members

Ms Maree Edwards — Chair	Mr Paul Edbrooke
Ms Cindy McLeish — Deputy Chair	Mr Bernie Finn
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Witness

Ms Carmel Murphy.

The CHAIR — Carmel, welcome to our public hearing this morning. Thank you very much.

All evidence at this hearing taken by the Committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege.

It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary.

I note that your submission mentioned your child. Are you okay for your child's name to be part of our public...?

Ms MURPHY — Yes.

The CHAIR — So we will hand over to you to make a brief statement.

Ms MURPHY — Thank you for inviting me here today. My daughter, Meg, is 13 and she has Down syndrome and autism.

The CHAIR — And she is gorgeous.

Ms MURPHY — Thank you. My husband Dean and I knew at 11 weeks into my pregnancy that we were having a girl with Down syndrome, so after four miscarriages and one successful pregnancy with our son, Ben, who is 15, my husband pointed out, "If you are going to have one with a disability, Down syndrome is the one you want." How true those words have become. We adjusted knowing I was giving birth to a disabled child and battled numerous doctors and specialists who recommended I either terminate or give her up for adoption. Statistics show 90% of pregnancies will abort a Down syndrome baby. There are only 67 reported Down syndrome births every year in Victoria.

While we were not deterred and I had 7 months to prepare, however she came six weeks early, an emergency caesarean and we were told if she survived the first three minutes, let alone the next 24 hours, we were doing well. Meg surprised us all and she thrived and our expectations were high. She was meeting all the milestones slowly and everything was great. Then at the age of two-and-a-half she stopped babbling, started rocking, went into a trancelike state for six months and was diagnosed with autism. I was very angry at the double blow and I couldn't understand how she could have both. We didn't sign up for that.

The challenges have been enormous, Meg is getting harder to manage as she gets older and we are struggling. Meg developed very aggressive behaviour and we've had to put her on one milligram of Risperdal daily. She has to be watched 24/7 and most days I feel like I have a 13-year-old baby.

Meg didn't have the typical Down syndrome traits and she wasn't fitting into the autistic basket, so we had her genetically tested for Kleefstra syndrome. We did this because you tick boxes when it comes to a diagnosis. However, Kleefstra syndrome came back negative and some other surprises instead. There were two mutations, a loss of 7Q31.1 and a gain of 9P24.1. A loss of 7Q31.1 has increasingly been reported to susceptibility towards ASD. Both my husband and I were genetically tested and Dean had exactly the same gene mutations as Meg. So what did this prove? That Dean was autistic too? I knew he was different, a bit anti-social, highly intelligent and fixated on one or two things but he was functioning well in the world and you wouldn't think he was any different to anyone else. I was happy having this outcome because I thought maybe Meg would be fine at the end of the day too. We've not had my son, Ben, tested because he was diagnosed with borderline Asperger’s at the age 8. We believe it was more anxiety and worked hard in conquering his fears. He has never wanted to be labelled and he refuses to think there is anything wrong with him. There isn't and he is well adjusted, confident and happy. Did I mention our dog has anxiety too?

The East Gippsland region is the last place in Victoria to roll out the NDIS in January 2019. I hope by then all the issues would have been ironed out and we can move forward with appropriate care for Meg. I have 7 recommendations needed in our area.

One, respite, respite, respite. Parents need a break from autism. It is draining, time consuming and highly demanding. We need to attract more staff with better pay. My respite team makes $20 an hour. I have applied for 30 hours extra over the school holidays and I have been told I will be very lucky this year to get that due to lack of funding and staff. There will be no respite on weekends. My husband has never taken a carer's day from work in 14 years but these holidays I will need him to take a few days. I never look forward to the holidays and six weeks is a long time for any child to be out of their routine, let alone an autistic child.

Two, socialising after school. Other than an all-abilities playground and an all-abilities netball team there is nowhere for our kids to go. Meg's peers have surpassed her and she has no genuine friends. It would be nice to have a dance group for our special kids in Gippsland, something like the e.motion, that the Down syndrome run.

Three, we need a community school in our region. Children with an IQ of 70 and under attend the Bairnsdale Specialist School who are currently the first in Victoria trialling the STAR program from America. The program includes strategies for teaching based on autism research. The principal indicates they are having enormous success. He suggests this program can be applied to all areas of our community and I'm really keen to see how this program develops. But the children that have an IQ between 70 and 85 are falling through the gaps or the kids that are just a bit different and maybe don't fit into mainstream. The ones that have behavioural issues and our broad spectrum of autistic children would be the most likely to benefit from a community school.

Four, behavioural support. We had an autism specialist who would visit the area and give local schools strategies to help autistic children. We need more workshops for parents with expert advice.

Five, access to cheaper equipment. It is all very well being told by my occupational therapist that your child would benefit greatly if they had more calming equipment within the home — a hammock, weighted clothes, climbing frames —Etc but, like a wedding, you mention special needs and the price of equipment doubles. We have spent thousands on Meg and due to her throwing everything in sight and we are up to iPad number 17.

Six, mentoring programs. How are our young adults going to enter the workforce without guidance and supervision? There is a need to develop programs in the community and give our children independence and show them how they can contribute and feel worthwhile do so. At this stage all I can see is Meg and I volunteering everywhere to fill in our day.

Seven, finally my biggest recommendation, have families genetically tested and work out if there is a common denominator in the results. The immunisation debate was forgotten after we received Meg’s results. Let's get some statistics, stop ticking boxes and work out how to help our autistic family. I can reduce chemicals in the home. I can maintain a gluten-free diet. I can introduce all the therapy needed and I can have a structured routine but what I want is funding to go into research and find a cure. I would love to know in my lifetime what causes Down syndrome and Autism. I have to agree with my husband, if you were going to have a child with a disability then Down syndrome is the one we would rather have. Thanks for listening.

The CHAIR — Thank you. Thank you so much and thank you for sharing Meg's story with us. Do you have a sense of how many children with Down syndrome also are diagnosed with ASD?

Ms MURPHY — It is growing.

The CHAIR — Is it a common co-morbidity?

Ms MURPHY — No, but it's been diagnosed more so. It was never for quite a long time but they are starting to recognise what is happening.

The CHAIR — And fortunately there is some research being done into genetics, which is great.

Ms MURPHY — I know. I am really happy to hear that. Pamie was telling me.

The CHAIR — It's early days, but it is starting to happen. You mentioned therapies and the interventions. Did they start from an early age?

Ms MURPHY — Yes.

The CHAIR — Can you describe what they were?

Ms MURPHY — We were the first ones to trial the FaHCSIA system but there were no service providers in our area so the $6,000 didn't go anywhere.

The CHAIR — You had to travel to Melbourne?

Ms MURPHY — No. We got the access to that funding for the autism but there were just no providers.

The CHAIR — So do you have a view on how the assessment and diagnosis for children with ASD and Down syndrome could be improved?

Ms MURPHY — That's an interesting one because already when you are born with Down syndrome you are perceived to have this intellectual disability and it wasn't until nearly two-and-a-half or three that we saw some other traits of autism and you think, not knowing, "Is that part of Down syndrome?" It is a bit confusing. So, I think, probably looking out for those typical signs of ASD at three.

The CHAIR — Did any of your therapists identify potential ASD?

Ms MURPHY — Speech therapist. We've had her since Meg was three and she saw some unusual things, especially the flapping and the rocking but just going into, like, a trance. She was a happy little girl until then and then just stopped one day. Just stared out the window and that was it.

The CHAIR — Do you have any parent or advocacy support groups?

Ms MURPHY — There are but I tend to stay away from them to be honest. I want to get away from things like that.

The CHAIR — You haven't engaged with...

Ms MURPHY — Again, because Meg doesn't fit into that Down syndrome basket — we have a Down syndrome support group and we have an autistic support group but we don't actually fit into either. I have some beautiful friends with both so that's where I get my support.

The CHAIR — School?

Ms MURPHY — School is brilliant. Our school is just sensational.

The CHAIR — Can you tell me a little bit about school?

Ms MURPHY — Paynesville Primary School is a mainstream public school and they have worked so hard and we have implemented so many strategies there and she is doing really well.

The CHAIR — What grade is she in?

Ms MURPHY — Six.

The CHAIR — Does she have one-on-one support?

Ms MURPHY — Yes.

The CHAIR — Is that a therapist?

Ms MURPHY — Just a beautiful lady that has worked with her.

The CHAIR — From the Department? Does she have training in autism or disability?

Ms MURPHY — No. She is just wonderful all the staff are, I could not fault them.

The CHAIR — How many students at the school?

Ms MURPHY — Now there are 115 and there is another child exactly like Meg and another little girl with Down syndrome and they have half a dozen autistic children. The reputation of the school is such that it is a great school.

The CHAIR — How did you decide on that school?

Ms MURPHY — We live around the corner.

Mr EDBROOKE — Which school is that?

Ms MURPHY — Paynesville Primary School. It wasn't easy to begin with. They weren't as accepting but because we worked so closely, all of us together, to put programs in place — the speech therapists, myself, the teachers — it was a battle to start with but they came on board and now we have set programs up for other children and it is working really well.

The CHAIR — Meg is on the DSV, she gets funding?

Ms MURPHY — Yes, she gets level 5 funding.

The CHAIR — And the NDIS, will she be on the list for NDIS?

Ms MURPHY — We have access to the ISP package at the moment of $5,000 for speech therapy. We have been on the wait list for three years from the DHHS for a larger package, which I've heard will roll over into the NDIS. So, just a timeframe.

The CHAIR — Have you given thought to secondary school?

Ms MURPHY — The specialist school is there and I'm waiting to see how...

The CHAIR — Which one is that?

Ms MURPHY — Bairnsdale Specialist School. I am waiting to see how the STAR program unfolds. I have been told by the Down syndrome Association that it doesn't matter which school Meg goes to as long as she fits in. My thoughts are she could stay at Paynesville Primary School for another three or four years, doesn't matter, but if this STAR program is what it says to be then it would be worth going across and trialling that.

The CHAIR — Thanks.

Ms COUZENS — In your list of seven recommendations, as you refer to them, you talked about the community school, can you expand on that a little bit more and tell us more?

Ms MURPHY — We don't have anything as such but at Paynesville Primary School, there are some great people there and they would love to extend next door to a type of community school that would reach out to all our children that are not fitting into the mainstream school, which there are several at Paynesville Primary, but they manage them really well.

Ms COUZENS — How many do you think that is in your community?

Ms MURPHY — In our community? It is a small community but I would say there are 15 children I could name right now that need help like that.

Ms COUZENS — Would you see something along the lines of the Dookie school?

Ms MURPHY — Yes, that could work too in our little community, yes.

Ms COUZENS — What other areas can the State Government do to improve access to support services for people with disabilities in your community, do you think?

Ms MURPHY — Offer higher pay. How are you going to attract people if you are not paying them? They are not getting paid enough. Why would they do that?

Ms COUZENS — So wages for professionals?

Ms MURPHY — Yes, absolutely.

The CHAIR — This is Paul Edbrooke, member for Frankston. Welcome.

Mr EDBROOKE — Does your daughter have any special interests?

Ms MURPHY — She loves horse riding. She loves swimming. She loves going to the Forge Creek Theatre when they have plays on and things like that — you have to show her everything. She doesn't just learn naturally. So we have to show her exactly what she could enjoy.

Mr EDBROOKE — How is Meg supported to undertake those activities? Is this a special horse riding school?

Ms MURPHY — The Paynesville Primary School takes her every second Monday to the Bairnsdale Pony Club.

Mr EDBROOKE — The primary schools do that?

Ms MURPHY — Yes, the Paynesville Primary School.

The CHAIR — Is that Riding for the Disabled?

Ms MURPHY — Yes, it is. I have an article here if you would like to read that after. They take her swimming every Thursday. They take her into the community shopping. They take her sailing, Sailability, on a Tuesday morning. They are just brilliant.

Mr EDBROOKE — Yes, they sound pretty good. The school sounds great. How has the transition or information on the transition on the NDIS been for you? Have you had many people provide information freely? Has it been hard to get? Are you confident with the amount of information you have got?

Ms MURPHY — Because we are the last for it to be rolled out I believe that Yooralla are starting to contact people. I certainly heard of one family that has been contracted in Morwell just recently. We have not been contacted. We get regular newsletters and updates but I'm just waiting to have that initial first contact, I suppose. I have been told it is January 2019 so Meg will be 16 by then. Our needs will be totally different to what we want now to what we need then. I can't get my head around it until such time as we are contacted.

Mr EDBROOKE — What was the experience like initially getting a diagnosis from a GP?

Ms MURPHY — For Down syndrome or autism, for both?

Mr EDBROOKE — Either.

Ms MURPHY — We knew when she was 11 weeks in pregnancy that she had Down syndrome, so accepted that. When she was diagnosed at three, through a paediatrician, that she had autism, that was a big blow. That was not what I signed up for. No, I didn't want that. No thanks.

Mr EDBROOKE — From that diagnosis were there clear pathways given to you as these people — advocacy?

Ms MURPHY — I think we were the first to trial the autism package it was available at $6,000. I remember battling to get my speech therapist even to get on the provider's list so we could use some of that funding for her, but it ran out of timeframe. I think I had to use it in two years or something.

Mr EDBROOKE — Thank you.

The CHAIR — You've had a bit to do with the Department of Health and Human Services over the years?

Ms MURPHY — M'mm.

The CHAIR — Can you tell us a bit about that experience and whether there's — what areas need be improved?

Ms MURPHY — They used to send out surveys when Meg was first born to say, "How are you coping? What are you doing? How are you feeling?" All that sort of stuff. I just said to someone the other day, "If they had have sent that same survey out to me now I'd be saying a lot different." because back then Meg was easy. It was easy. I was too proud to even take anything in the beginning. I just thought, "We will be right. We chose to have Meg. We will run with it." Then when she was diagnosed with autism I thought, "Oh, hello, we will need more help here." So that's when we got onto the DHHS and then we got our first flexible support package and then we got our first individual support package and that little bit has helped us to get the speech therapist who works with our school, and who works with other children. The last three years we've upped the package but there is no funding, of course, and it is all just put on hold until the NDIS rolls out. I'm not holding my breath at the moment.

The CHAIR — Which of the therapies that Meg has accessed would you say was — were the most beneficial?

Ms MURPHY — Speech therapy, occupational therapy.

The CHAIR — Was that in terms of her ability to communicate?

Ms MURPHY — She has only just started talking in the last two years. We didn't really think she would.

The CHAIR — Is that because of the speech therapy?

Ms MURPHY — A number factors and a number of issues. She has dysphagia in her mouth. She can't chew properly because of the bigger tongue and those sorts of hindrance problems that she has.

The CHAIR — So Meg's never had any ABA therapy?

Ms MURPHY — No. I don't know what ABA is.

The CHAIR — I have no more questions. Thank you so much for sharing your journey with us today, and Meg's journey as well. It is much appreciated. Good luck with everything. It sounds like you've got her in a fantastic school.

Witness withdrew.